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ABSTRACT

In 2002, the Bazelon Center for Mental Health Law investigated the impact of expanding child mental health services in Medicaid on the actual availability of services to children. To assess family satisfaction, focus groups were held in two states: Oregon and New York. Both states have a comprehensive Medicaid mental health benefit for children with serious disorders. This report summarizes findings from the New York focus groups. The families who participated reported that they generally found Medicaid-covered services helpful--when they are able to get them. Many child mental health service providers do not accept Medicaid. While some of their children had access to special programs that provide particularly helpful services, most of the focus group families found obtaining mental health and supportive services for their child extremely difficult. In most cases basic treatment (medications and therapy) was relatively more accessible, but in-home services were generally unavailable to families unless they had access to one of the few slots in the state's Medicaid home- and community-based waiver program. Parents in all three groups said they had often tried in vain to make providers aware of their child's problems. Deficiencies in New York's approach to children's mental health services have led to a system where children repeatedly--and parents felt, needlessly--go into crisis. The parents drew a picture of a system in New York State that wastes precious human and financial resources by making it so difficult for families to raise their children at home and to ensure them appropriate education and health care as they grow up. Two appendixes contain the focus group methodology and data tables. (GCP)

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ASSESSING CHILD MENTAL HEALTH SERVICES IN NEW YORK

A REPORT ON THREE FOCUS GROUPS

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The Bazelon Center for Mental Health Law is the leading national legal advocate for people with mental disabilities. Since its founding in 1972, the nonprofit organization's precedent-setting litigation and public-policy advocacy has successfully challenged many barriers and expanded access to public schools, workplaces, housing and many other opportunities for community life. Today we work to end the punishment of children and adults for the failures of neglectful public mental health systems and to achieve full membership in the community for all people with mental disabilities.

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EXECUTIVE SUMMARY

Over the past decade, services for children with serious mental disorders* have become significantly more effective. Today, many interventions can be provided in the community, enabling many children to live at home. Recognizing the need to cover these services, states have adjusted their Medicaid programs accordingly.

Because of these changes, a broad array of children's services in public mental health systems is now covered under the Medicaid category of rehabilitation services. State Medicaid programs today finance a wide range of evidence-based community mental health services for children, including medical and clinical treatment and various rehabilitation services.[1]

Clinic services include services by physicians and other mental health professionals, such as medication management and psychotherapy. Rehabilitation services include many types of intensive programs furnished to the child in natural settings, such as school, home and the community.

Children on Medicaid are entitled to any necessary health service covered under federal law, whether or not listed in a state's Medicaid plan. However, this does not ensure that children will actually receive the services they need and to which they are entitled. Whether children can access these covered services depends on the availability of the services in their community.

My dearest wish is for my son to be able to be maintained at home. He's been at residential facilities and hospitals on and off since he was seven years old. I have asked for support from the county and have been denied any kind of financial support. I've been denied and told that there were no services available, period, to maintain him in the home. The county had the money to maintain him in a residential facility or a hospital, but not maintain him at home. So my dearest wish would be a home- and community-based waiver [slot]. (Summit parent)

Independent commissions and task forces across the country are increasingly identifying significant problems in public child mental health systems that raise serious questions about whether children with serious mental disorders are actually benefitting from their Medicaid entitlement.[2] The expansion of Medicaid service options, while encouraging, may mask an opposing trend—reduction, or at least lack of expansion, in availability of the services needed by children with serious mental disorders.

In 2002, the Bazelon Center for Mental Health Law, with funding from the W.T. Grant Foundation, undertook to examine whether the expansion of child mental health services in Medicaid had actually increased the availability of services to children. This is challenging to ascertain, but families' perceptions can provide a significant indicator—and can help the public understand a complex matter of public health policy. To get a snapshot of families' experiences, we convened focus groups in two states: New York and Oregon. Both have a comprehensive Medicaid mental health benefit for children with serious disorders. This report summarizes findings from the New York groups.

We convened focus groups of families receiving Medicaid in three areas of the state. One was held in Manhattan for parents in the five boroughs of New York City, one in Summit for parents in rural Schoharie County and one in Syracuse for parents in mainly urban Onondaga County.

* The term "mental disorders" as used in this report refers to mental illnesses and emotional or behavioral disorders but not to mental retardation or other cognitive disorders.

The families who participated reported that they generally found Medicaid-covered services helpful—when they are able to get them. Many child mental health service providers do not accept Medicaid. While some of their children had access to special programs that provide particularly helpful services, most of the focus group families found obtaining mental health and supportive services for their child extremely difficult.

Parents in Schoharie County reported the greatest difficulty. Schoharie County is rural, with extremely limited child mental health resources. It has only one small clinic with a part-time psychiatrist. Some of the families said they waited three to five months before their children even got diagnoses. Parents stated that, as far as they know, only four case managers were available for all of Schoharie County. They also recounted problems with transportation to service sites (a Medicaid-covered service).

New York City participants also complained of poor access to services, although several of the families in this group said they were able to get the services their child needed through access to one of a number of special programs. Parents enrolled in Health Maintenance Organizations (HMOs) reported difficulty in obtaining adequate services for their child because HMOs are responsible only for a minimal level of mental health care for children enrolled in their plans. Children with complex mental health needs are entitled to the more expansive benefits available under fee-for-service Mediciaid, and some parents reported that their children were able to opt out of the HMO plan and instead access these benefits. Other parents were unaware of this possibility.

Most families in the Syracuse group stated that they could access some services, but that these services were often insufficient to meet their children's mental health needs.

Parents in all three groups said that access to intensive rehabilitation services, such as day treatment or therapeutic foster care, was extremely limited, even nonexistent. In most cases, they said, basic treatment (medications and therapy) was relatively more accessible, but in-home services were generally unavailable to families unless they had access to one of the few slots in the state's Medicaid home- and community-based waiver program. Intensive school-based services were also very scarce, and many of the parents reported that entire school districts have no day treatment for these children.

Providers' failure to recognize children's problems in a timely manner or to offer services before children go into crisis exacerbates family problems. Parents in all three groups said they had often tried in vain to make providers aware of their child's problems. They reported particular frustration with providers' lack of attention while the child was very young.

Many families believed that the system offered them insufficient assistance or information in how to manage their child's disorder. They felt that instead they were blamed for the child's disorders and that their perspectives were ignored as they sought services for their child.

Deficiencies in New York's approach to children's mental health services have led to a system where children repeatedly—and parents felt, ***needlessly***—go into crisis. Without earlier intervention, children's conditions worsen, making necessary more intensive, and therefore more expensive, mental health services. Families recounted a significant lack of intensive services, such as day treatment.

As children age without receiving adequate mental health and supportive services, parents reported becoming more desperate and less able to cope with the child's disorder. To their great distress, many of their children eventually wound up in state custody through the child welfare or juvenile justice system.

The parents drew a picture of a system in New York State that wastes precious human and financial resources by making it so difficult for families to raise their children at home and to ensure them appropriate education and health care as they grow up. The inevitable result is a need for more, and more costly,

services from mental health, child welfare and juvenile justice systems.

The factors that parents cited as barriers to needed services include:

- failure to identify and assess children early;
- an overemphasis on basic medical and clinical treatment;
- lack of appropriate providers;
- failure to individualize care;
- lack of treatment planning for children being discharged from residential settings; and
- poor collaboration across systems.

Some of the parents reported that their children were served through special programs, such as the Friends program in New York City, that offer a broader package of services and are more supportive. Another program, the Coordinated Children's Services Initiative, funded through the state's Office of Mental Health, consolidates services from various agencies to create a coordinated system of care for a child. Some families receive services under a waiver of federal Medicaid rules to provide home- and community-based care to children who would otherwise be hospitalized. Families in each of these programs reported more access to services than those who are not, but all three programs have a limited number of slots. As a result, most parents in the focus groups were left with restricted care that achieves minimal, if any, result.

The Bazelon Center suggests several ways to improve New York's public system of children's mental health services, including:

- Substantially increase the number of families who can benefit from the home- and community-based waiver program. Currently, only 610 slots are available to families across the entire state; 907 children were served through these slots in 2002.
- State investment in intensive community rehabilitation services would help address the dearth of such services. Parents expressed a specific need for increased access to day treatment, in-home service providers, after-school and summer programs.
- Develop a better response system to address children's mental health crises. Expanding the use of specialized mobile crisis teams could provide effective interventions that can often make expensive inpatient or residential care unnecessary.
- Consider developing additional systems of care similar to the Friends program and other federally funded initiatives. The state already has one other federal grant (in Westchester County), but more communities could benefit from such grants.
- Strengthen and expand the Coordinated Children's Services Initiative (CCSI) to pool resources from child-serving agencies and involve families in all service planning.

Because children with complex needs are unlikely to benefit from the short-term acute treatment normally offered through HMOs, it is important to identify the children who require—and are entitled to—the more expansive benefits available under Medicaid fee-for-service. Families of these children need more information on this, and managed care entities should be obligated to refer children to the public mental health system where appropriate. In fact, the parents of children with severe disorders who remained in their managed care entity reported the greatest dissatisfaction with New York Medicaid.

In other areas, a modest effort by the state could significantly improve services for children with serious mental disorders. For example:

- Greater emphasis on training of non-mental health professionals, such as teachers or child welfare caseworkers, could improve their understanding and recognition of mental disorders in children and enhance their ability to make appropriate referrals for care.
- Closer collaboration between mental health providers and primary care physicians would improve early identification of children who need mental health services. Development of an effective screening tool for mental health and substance abuse issues for use in busy pediatricians' offices might facilitate this and more

effectively meet Medicaid's mandate of screening all eligible children for mental as well as physical disorders.

- Developing and enforcing criteria for appropriate discharge planning from hospitals and residential programs would help families address transition issues when children with mental disorders return to life at home. Planning for the child's transition back to his or her home school district and engaging community case managers prior to discharge can be extremely helpful to families.

In addition to suggesting areas where policies might benefit children and families, the focus groups highlight some of the state's underlying difficulties in improving access to services.

Many parents in the focus groups discussed the dearth of psychiatrists, psychologists and other mental health providers appropriately trained in child mental health. This is a greater problem in rural areas, but appears to present challenges in urban areas as well. The state needs to develop plans to address this deficit.

Transportation issues pose a significant barrier for many parents in the sizeable rural parts of the state. Development of services closer to where families live can be one answer to this problem, but when this cannot be done there may be more creative ways for the state to assist families in accessing other forms of transportation or to provide short-term overnight accommodations when long distances must be traveled.

CONCLUSION

New York's Medicaid state plan includes a strong mental health benefit for children, covering most of the important community mental health services needed by children with serious mental disorders. However, as illustrated by the comments of the parents in our focus groups, the benefit is unavailable to many families. Even when these families had access to basic medical and other outpatient treatment for a child, they often lacked access to the community service package their children need to live successfully at home.

Services are too often denied or delayed until a crisis results, the families complained. And when children experience a psychiatric crisis, the response is often inadequate, with very limited access to intensive services and residential care. Delayed identification and inappropriate responses to children and families have led to a crisis-oriented system in New York.

Without adequate mental health and supportive services, many children continue to deteriorate despite the efforts of the loving and supportive families who participated in these focus groups. Tragically, too often such children end up in the juvenile justice system, punished for the system's failure to adequately address their mental health needs.

New York's children deserve better.

INTRODUCTION

New York provides Medicaid mental health services through a fee-for-service system. Medicaid-eligible individuals are also enrolled, through the Partnership Plan, in managed care entities (HMOs) that are responsible for their physical health care. The HMOs also provide a limited, acute-care-focused, mental health benefit of 20 outpatient visits and 30 inpatient days.[3] However, HMOs are not responsible for mental health care for children with serious mental disorders and those who qualify for Medicaid through the Supplemental Security Income (SSI) program. All of these children's mental health care is furnished through fee-for-service providers.

Some New York City boroughs and Schoharie and other counties in upstate New York currently do not have any managed care. In these areas all mental health services are provided through fee-for-service.

New York is one of only three states with a Medicaid home- and community-based services waiver that covers children with emotional disturbances. Since 1996, the waiver has served a limited number of children between 5 and 17 years old who are at risk of requiring institutional care. In 2002, 907 children were served through this waiver. Of the three counties studied, waiver slots were allocated only in New York City and Onondaga County.

In addition to the six waiver services listed in the box on this page, flexible-service funds (also referred to as "wraparound funds") are available to purchase items and services needed to achieve the goals in the service plan of a child under the waiver.

A number of state agencies have collaborated to establish a Coordinated Children's Services Initiative (CCSI) that provides service planning and assistance to families of children with serious mental disorders. CCSI, initiated in 1994, is designed to reduce out-of-home placement of these children through interagency planning and integrated service delivery. Its focus is to eliminate service duplication and ensure that families

MENTAL HEALTH SERVICES IN NEW YORK STATE

Like other states, New York covers a wide array of community mental health services under its Medicaid Clinic and Rehabilitation options. Medicaid-covered community mental health services for children in New York are as follows:

OUTPATIENT CLINICAL CARE

- Assessments
- Individual and group psychotherapy
- Family support
- Crisis services
- Partial hospitalization
- Physician services, including medication management
- Prescription drugs

24-HOUR INSTITUTIONAL CARE

- Psychiatric hospital inpatient services
- Residential treatment center services
- Group home services
- Therapeutic foster care
- Teaching family homes

REHABILITATION SERVICES:

- School-based day treatment
- Other day treatment
- Therapeutic preschool
- Therapeutic foster care
- Independent living skills training

CASE MANAGEMENT

- Targeted case management for children with serious emotional disturbances

HOME AND COMMUNITY-BASED WAIVER

- In-home services
- Individual care coordination
- Respite care
- Family support
- Crisis response
- Skill building

Table 1: Public Programs by County, 2002			
	New York City	Onondaga County	Schoharie County
Fee-for-Service	✔	✔	✔
Partnership Plan (HMO)	✔	✔	
Home and Community-Based Waiver	✔	✔	
CCSI	✔	✔	✔

have what they want and need to maintain their children in the community.[4] CCSI is available for any child who is referred by one of the participating agencies, whether Medicaid-eligible or not.

Each county has its own criteria for participation in CCSI. To a degree that greatly varies across counties, county CCSI coordinators can pool funding from participating agencies to organize the wraparound services needed by children who are served by multiple agencies. The various state agencies involved include the Office of Children and Family Services, the Council on Children and Families, Division of Probation and Correctional Alternatives, Office of Mental Health, Office of Mental Retardation and Developmental Disabilities, the Office of Alcohol and Substance Abuse Services, the State Education Department, and the Department of Health.

Families are specifically involved in all levels of service planning.

Table 1 (above) presents information on public programs for children in each of the counties where focus groups were held.

THE BAZELON CENTER STUDY

In June 2002, the Bazelon Center convened three focus groups composed of parents of 40 children with serious mental disorders who are on Medicaid. One group, representing 20 children, was held in Manhattan for parents in the five boroughs of New York City, one in Summit for the parents of 11 children in rural Schoharie County and one in Syracuse for parents (nine children) in mainly urban Onondaga County.

Parents completed a short survey regarding their child's disorder and use of mental health services. For more information on the focus group methodology, see *Appendix B.*

FOCUS GROUP PARTICIPANTS

Eighty percent of the participating parents were mothers. Their children were primarily male (65 percent) and tended to be older:

- 33 percent were 7-12;
- 65 percent 13 -18; and
- only 3 percent were under 7 years old.

The children's race and ethnicity were slightly different from the children's in the state as a whole: 46 percent of the participants' children were white, compared to 62 percent of children in New York State; 33 percent were African-American (compared to 19.3 percent statewide) and 26 percent Latino (statewide, 19 percent).[5] None of the children were Asian.

Eighty-five percent of the children had more than one mental health diagnosis. The diagnoses most often reported by parents were:

- attention-deficit/hyperactivity disorder (ADHD) or attention deficit disorder (ADD), 65 percent;
- depression, 63 percent;
- learning disorder, 58 percent;
- conduct disorder 40 percent; and
- oppositional disorder/oppositional defiant disorder, 33 percent.

FINDINGS

ACCESS, AVAILABILITY AND APPROPRIATENESS OF SERVICES

Families reported that they found Medicaid-covered services helpful—when they could get them. While some of the families had access to special programs that provide particularly meaningful services, most said that obtaining services for their child was extremely difficult.

Of the three groups, the parents in Schoharie County reported the most difficulty. The county is rural and parents reported that it has very limited child mental health resources, consisting of only one small clinic with a part-time psychiatrist. Some of the families said it took three to five months to get an initial appointment for their child. Parents in Schoharie County reported that they knew of only four case manager positions in the entire county. They also found transportation to services problematic.

It's like three months [The wait for an evaluation] and it varies. Three to five months for an intake evaluation. Then you have to wait three weeks while they have their staff meeting and they take the appropriate testing or whatever. (Summit)

Most New York City participants, too, complained of poor access to services, although several said they were able to get services their children needed. Most families in the Syracuse group could access some services, but said these services were often insufficient to meet their children's needs.

Parents in all three groups reported that access to intensive rehabilitation services (see list on page 5) was extremely limited or nonexistent. In most cases, basic treatment (medications and therapy) was more readily accessible, but in-home services were generally unavailable to families, unless they were part of the state's limited home- and community-based waiver program. Intensive school-based services are also very scarce, the parents said, with many school districts having no day treatment for these children.

Parents in all the groups complained about providers who ignored their child's problems, especially when the child was very young. This failure to act before children go into crisis exacerbates family problems. It also means that the services the child eventually does receive will have to be more intensive and more costly to the state.

She [at age 5] tried to put a pillow over a child's head to kill her. Now that she attempted to kill children and was a risk to herself and others have I finally got a mental case worker. (Syracuse)

Many providers do not accept Medicaid. This presents yet another barrier for families seeking mental health services for Medicaid-eligible children.

Many families believed that the system offered them insufficient assistance or information in how to manage their child's disorder or proactively deal with problem behavior. They felt that they were instead blamed for their child's disorder and that their perspectives were ignored as they sought services for their child.

Deficiencies in New York's approach to children's mental health services have led to a system where children repeatedly—and, the parents felt, needlessly—go into crisis. Without earlier intervention, they reported, children's conditions worsen, making necessary more intensive, and therefore more expensive, mental health services. But families said they must often wait months for a bed in a residential treatment center.

As children get older, parents become more desperate and less able to cope with their child's disorder at home. According to the parents, many of the families eventually have no recourse but to consign their child to state custody through the child welfare or juvenile justice system—a tragic outcome, confirmed by the Bazelon Center in many other states.[6]

The Bazelon Center's focus groups demonstrate how deficiencies in New York's child mental health system waste precious human and financial resources while imposing extreme difficulties on families who are struggling to keep their children at home and ensure that they have appropriate opportunities in their lives as they grow up.

I feel if I had gotten some kind of home-base services when my child was beginning or starting with his greatest need at age 5, because he went into foster care, because I just was not able to handle what was happening at the time, he was just so overwhelming. But if I had somebody to come into my home and teach me...certain things that I should know about my child, that it would have helped. (Syracuse)

MOST FAMILIES HAVE LIMITED ACCESS

While parents whose children had access to services beyond clinic-based treatment were often pleased with the quality of the care, most focus group participants found obtaining needed mental health services for their children to be difficult. Some reported that their child's need for services was denied, or services were approved but providers were unavailable. In other cases, families waited months to see providers.

Access problems varied in the different areas. Parents in Schoharie County had the hardest time accessing care. They reported that mental health services were severely limited, consisting of just one small county clinic and no psychiatric inpatient or residential facilities. The mental health clinic had one part-time psychiatrist and long waits for services were common. Parents reported typical waits of three to five months for an initial diagnosis. They knew of only four intensive case managers in the county.

One parent summed up the group's experience:

We had to go out of county for all of our school and day treatment services. There are absolutely no services available in our county for my son, period. (Summit)

Families in the Syracuse area generally fared better. The Onondaga County parents reported that, although none of the specialty mental

My thing was, just to get him into the therapy right away, to go to the emergency psychiatric... Nobody would help me. I said, "He needs therapy." That's the reason I had to go there...I just hope I don't have to go through that just to get treatment because he needs therapy, but I don't know where to go. (NYC)

health services were easy to get, they could generally find a psychiatrist and a therapist. However, they had little choice among these providers.

While Onandaga County offers services under the home- and community-based waiver, few families in the focus groups receive in-home services due to the waiver's limited number of slots. The wait list was between eight months and a year-and-a-half, they reported. Only 19 percent of children in the focus group families had received in-home services during the past year.

The New York City group described mixed experiences, depending on whether a child was in an HMOor Medicaid fee-for-service or had access to innovative initiatives such as the Friends program. The families who were enrolled in an HMO reported considerable difficulty in getting their children needed mental health services. Several families had switched from the HMOs into Medicaid's fee-for-service approach for this reason, and they reported improved access to services for their child.

They tell me no. You have to wait. You have to wait. There's a long list [for therapy]. (NYC)

Language concerns presented difficulties for some New York City participants. Spanish-speaking families reported great difficulty finding Spanish-speaking mental health providers or providers with interpreting capability. Six Hispanic families in one focus group were highly satisfied with the services they received from the Friends program. This program began as a federal Center for Mental Health Services' (CMHS) Systems of Care project, and is now funded by the New York State Office of Mental Health. Friends provides comprehensive services, including case management, crisis services, family support and education, and wraparound services—all designed to avoid out-of-home placement. The Friends program has a diverse staff that is able to serve the heavily Hispanic and African- American Mothaven area in the south Bronx.

While not a significant problem in heavily urban New York City, transportation was a crucial barrier for the families in Schoharie County. Medicaid-eligible families could obtain transportation by calling a toll-free phone number, but they had to do so a week in advance. Taxi service was available in emergencies, but many families said they had not known of that.

Sometimes when they tell you this is all they have to offer, this is the best they can do. I've gotten to the point where I tell them, I want more than this, I want you to offer something different. It's not working. [They say] well, it's going to have to work. [I reply], no, it's not going to have to work, you're going to do something different. I want him to go some place different. I want different medication. (Syracuse)

In all three groups, a few exceptionally persistent and assertive parents said they had been able to get their child services after considerable time and effort. One parent even moved to a different borough in New York City to obtain services for her child.

WHEN SERVICES ARE AVAILABLE, FAMILIES FIND THEM HELPFUL

While the families reported significant problems in accessing services, those who did secure Medicaid-covered mental health services for their

children often found them helpful. Focus group participants cited several services as being meaningful, including:

- therapy;
- psychosocial rehabilitation services;
- family education; and
- mobile psychiatric crisis teams.

I have had good experiences. My son is on the medication Ritalin. He has been under therapy. For three years he was under that medication, and he's doing fine. So I thank the services for that. (NYC)

The home- and community-based waiver services and the integrated services received through the Coordinated Children's Services Initiative (CCSI) were seen as particularly helpful. For example, parents whose children were served under the waiver appreciated the availability of respite, more frequent services and services provided in the home. Although only a few of the children of parents in the focus groups were served under the waiver, many other parents knew of the waiver and what children could receive through it, such as in-home and school-based services. These parents felt strongly that their own child needed these services.

Medicaid has been pretty good for me also. There is usually like a two-month waiting list for services. But once the services starts [sic] it's pretty good. They cover almost all his visits. (Syracuse)

One fourth of the children represented in the focus groups participated in CCSI and their families were generally satisfied with the coordination of services. Some parents reported that CCSI meetings were the first time they had been able to get all providers and agencies involved with their children to sit down together.

LACK OF ACCESS LEADS TO A CRISIS-ORIENTED SYSTEM

Parents expressed concern that many children with serious issues were served only when their condition deteriorated. Early intervention was scarce and little was available for children with the most severe disorders beyond basic and largely infrequent outpatient treatment visits.

Many parents reported that providers would not believe that their young children could behave in extremely violent ways or exhibit signs of psychosis. Families often waited years between the time they identified a serious problem and sought services, and when a mental health provider recognized the seriousness of the child's disorder. During this period, parents typically saw their child's condition worsen.

I am concerned about services. I don't want to lose my son. I want to get my son help now before he goes and robs a store or something and then he gets taken away. (Summit)

And he said, "Well, you can take your son home. Call mental health in the morning." Which I did. And I got kind of like the run around a little bit. And I'm standing here – what do you do now? I had a crisis last night with my son. He could have killed himself or a member of the family. Here he is watching Sponge Bob and I'm wondering if he's going to kill himself today. (Summit)

The lack of services caused other disruptions in family life. In many cases, parents said they became the front line of New York's service delivery system as they were left to deal with their child's serious disorder with limited or nonexistent services to support their efforts.

Once we zeroed in and found some nice people with some kind of heart. One social worker, she said, "I'm going to help you because you've been through so much and you've been thrown here and here. I don't want her to go through the system, get caught up in it. She needed to get the help she needed." She helped me. (NYC)

I had to leave my job, take a leave at home and be held hostage in my own home for a whole year before he was even considered. Then they told me he was on a list. I didn't even believe them because how could I? I had lost all hope. (Syracuse)

ASSESSMENTS AND DIAGNOSIS ARE KEY, BUT VERY DIFFICULT TO OBTAIN

The first challenge parents face is obtaining a mental health diagnosis for their child—something the parents in all three focus groups reported was extraordinarily difficult. Parents wanted more timely and more accurate diagnoses, and they wanted to be educated about the child's disorder.

Parents expressed concerns that the lag in diagnosis resulted in situations where children entered the system only when they were in crisis:

To get him to go to the clinic and to get a psychiatric evaluation, you have to see the therapist more than 15 times before they can grant you a psychiatric visit. It's been very frustrating and very difficult. (NYC)

My mental caseworker said, "I hate to tell you this, but I think they're going to wait until she gets into first grade where you have to put her in public school and wait for her to do something, either kill a child or do something very bad before the district will notice that she needs to be placed someplace else appropriately." And I don't want that to happen. I'm seeing Columbine. I'm fearing my child is going to hurt herself or somebody. (Syracuse)

OUTPATIENT VISITS FOR THERAPY AND MEDICATION ARE AVAILABLE, BUT LIMITED

Once a diagnosis was established, parents said, visits to physicians and other mental health professionals for basic outpatient services such as counseling, medication and medication management could usually be scheduled. However, they reported that it was much more difficult to access more intensive services for their children.

Although 79 percent of children had received counseling in the past year, many parents found that the frequency and quality of counseling were insufficient to address their children's needs. Children typically received counseling only once or twice a month.

One parent who was aware of the right to file a grievance was able to get the counseling services that his son needed:

[The clinic] wanted my son to come in every two weeks. I said no. If I have to file a report against you people because he needs it once a week, not twice a month, I said I'll be happy with once a week, I said I will file. I got what I needed, I didn't have to file. (Syracuse)

Parents said the number of counselors available to work with their children was limited. Counselors changed frequently, making long-term counseling difficult and disrupting relationships between counselors and children. The parents became frustrated at having to explain their child's situation over and over.

They'll tell you that you can no longer go to that therapist. Then you have to wait again to start with another therapist. So that's been kind of a battle for me finding a therapist that my son can link up with and stick with. (Syracuse)

Psychiatrists were difficult to find because so few were willing to accept Medicaid. Psychiatrists who did accept Medicaid often limited the number of Medicaid patients they saw and many were not accepting new patients. Families said they often experienced months-long waits to see a psychiatrist. The scarcity of psychiatrists made it very difficult or even impossible for them to change providers if they were dissatisfied with the one treating their child.

But the child psychiatrist is an iffy proposition. That goes back and forth. Sometimes there's one and sometimes there isn't. (Summit)

CRISIS SERVICES ARE INADEQUATE

More than half (58 percent) of the children received crisis services in the past year, according to parents. Parents usually went to the mental health clinic during weekday business hours. To deal with after-hours crises, they went to a hospital emergency room or the police.

I would wake up and my house would be totaled. He would have crayons and pen marking all over the wall, everything would be torn apart. And I would take him to the park and I would say come on time to go home. And when I took him to daycare centers he would hit children over the head and get thrown out. He got thrown out of every daycare center he was in because he was confrontational with other children. He just couldn't get along with the other children. I took him to his pediatrician and they would not diagnose him or put him on any medication or anything until he was age 5. (Syracuse)

The quality of crisis services varied. In Onondaga, the mental health emergency room has no staff able to address child and adolescent psychiatric issues. Because Schoharie County has no hospital with a psychiatric unit, children are funneled to the criminal justice system by default; parents must first call the Sheriff's Department, which then contacts the mental health clinician on call at the clinic.

Whatever the system for coping with crises, parents complained that there were long waits and that little evaluation or treatment was available for children through existing crisis services. Many children were just sent home with a referral for outpatient treatment.

Many parents expressed the need for 24-hour mobile crisis services staffed by mental health providers who are trained to treat children and adolescents.

INTENSIVE HOME AND COMMUNITY SERVICES ARE GENERALLY UNAVAILABLE

Most of the parents said that the intensive rehabilitation services needed by children with serious mental disorders (see list on page 5)

were unavailable to their children. Many felt they could keep their child at home if in-home services, intensive case management or day treatment were available.

These types of intensive services furnished in the home of children and youth with serious mental disorders can greatly assist families in handling difficult moments with their child. Home-based services can ease the transition for children with serious mental disorders between the structured school day and their home. Many of the New York City parents said that these critical services should be both more widely available and not be limited only to children served by the home- and community-based waiver.

I thank the waiver services because they are very intense services and it has helped me a lot with the waiver, to have them come into your home. It's been very, very helpful. (NYC)

In many cases, families were expected to cope at home with children whose disorders were extremely serious, and yet they reported having no supports and their child, no services.

> *He came home on a stipulation that he was going into residential placement. So he came home to us for a six-month period knowing that he had to go into residential placement, but there wasn't any wraparound service. There was nothing offered to us. We just had to take this child home that was supposedly so out of control and unstable that he had to be in residential placement. And keep him safely at home until that period in time when a placement became available. With no services offered to us except for counseling at the clinic. That was all we were offered. (Summit)*

Some parents described the release of their children from an inpatient unit without any follow-up services and without coordination with the other public agencies involved with the child's case, such as the school district.

> *They sent my nephew home...with no discharge plan whatsoever. I had a child that was suicidal and was a potential perpetrator, and was becoming violent and they sent him home with nothing. (Summit)*

We had an awesome intensive case manager. She was very supportive of us. She came to our home and even after she was not our intensive case manager, she still called and checked on [him]. And to this day, she still cares what happens to him. (Summit)

Case managers can be of great assistance to families, and parents said that more than half (61 percent) of the children received case management services. These parents understood that case managers were essential in helping to find and get the child into the limited services that were available.

However, many families waited at least two months for a mental health case manager. Other parents said they could have used a case manager but didn't get one.

Many of the parents felt that respite—a service now covered only for families in the waiver and not generally available to other families—would be especially helpful. Families expressed the wish that child respite

services be added to the array of standard Medicaid community services covered.

I think there should be a respite, across-the-board respite program covered by Medicaid for when you have children under, say like under 12 or 13 when you need a break and somebody can come in and be with your child and let you just, even go out for lunch or go to the library when you have a kid. (Syracuse)

When my son got into Onondaga Case Management, I felt like one of the lucky ones that didn't have that long of a wait. Maybe it's because I got loud and very demanding. (Syracuse)

SCHOOL-BASED SERVICES

Families generally felt that school-based services were inadequate. More than half (54 percent) of the children received some type of school-based mental health services during the past year, the parents reported—usually counseling. However, most schools lacked appropriate staff, particularly psychologists, they said, and programs to evaluate and handle children with serious mental disorders. Few of the children and adolescents represented in the focus groups were in day treatment programs run by either the mental health system or the schools.

Some of their children's schools refused to conduct psychological evaluations, the parents reported, speculating that this was to avoid the financial responsibility to provide special education.

Parents also complained that schools often would not work with the family until a child exhibited difficulty in the school.

But because it wasn't severe trouble in school, they didn't want anything to do with it. They simply handed me the same line: "As long as he isn't acting out in school, we can't do anything about it." Not until he sexually attacked somebody in school and started verbally abusing people did they do something about it. (Summit)

I work in a school that is the only one in Syracuse that provides [for the needs of] emotionally disturbed children. We are very fortunate to have a psychiatrist, many counselors, mental health services, social worker, all different people... But the rest of the schools, and there are so many here in Syracuse that do not have that kind of service for our children who are emotionally disturbed or who have mental illness or have problems before they go into regular school. (Syracuse)

Parents told us that day treatment programs were completely unavailable in several school districts. Onandaga County districts had only one day treatment program, and Schoharie County districts had none. Several of the parents sent their children out of the county and even out of state for day treatment programs. However, some Onondaga County parents found that schools provided the help their children needed. Also, some of the parents had children in schools where there was a mental health provider.

FAMILIES LOOK TO RESIDENTIAL SERVICES

We've had to go out of county for all of our school and day treatment services. There are absolutely no services available in our county for my son, period. (Summit)

Parents had mixed views about residential care. Because community-based services are so limited, many parents said they had sought residential treatment when they could no longer cope with the child's symptoms and behavior at home. However, they often had to wait between a year

and a year-and-a-half to get their child into a residential treatment center service. These delays created additional difficulties for families because their children had to stay in the community without adequate services or support even though they met the criteria for residential care. Families who allowed their child to live in a facility out of the county or out of state said their wait was shorter.

My nephew is in [another state] for services because no services for him were available –neither in the county or in the state. (Summit)

> *It didn't take long– a couple of months. But he didn't go to Syracuse. He's in [another city]. That's why. Syracuse only has 18 beds. And there is a waiting list. Probably two years. But if you're willing to let them go out of the area. (Syracuse)*

Once their child was in a residential treatment program, a few parents reported that it was the first place where their child had been diagnosed and received helpful services.

However, several parents of children who had been in residential treatment expressed concern about inadequately trained staff.

> *There was one incident where a staff person allowed my son to stay up to 3 o'clock in the morning and then get up to 5:30 or 6 o'clock. He was very rough getting my son up that early in the morning for school. You don't expect a child to stay up that late and get two or three hours sleep. My son went off and injured the staff person and put him in the hospital. I think some of the people that work in residential care, I don't think they're fully qualified. (Syracuse)*

Residential was tremendous help for my son. [The child] was truly diagnosed there... He learned so much there... Really, residential treatment helped my son tremendously. (Syracuse)

INPATIENT TREATMENT IS LIMITED

Many parents reported that, when they did have to resort to inpatient care, their children were not offered sufficient inpatient treatment to address an acute problem adequately. Several parents were extremely upset that a discharge plan was usually not prepared prior to the child's return to the community.

> *Many times it's requested that the discharge plan be available for children when they are discharged from the hospital and they are expected to go back to school based on the discharge plan. But you don't get the discharge [plan] usually for at least 10 days after the release from the hospital. So here these kids are sitting at home for at least 10 days and they're not allowed to re-enter back into the community. (Summit)*

We were just talking to our therapist about the fact that hospitals don't like to keep children on Medicaid in psychiatric hospitals for long stays because they don't get the reimbursement that they get from insurance companies. So they try to pressure these kids in and out of the hospital at a very rapid rate. (Summit)

Some parents who obtained discharge plans for their child did so either through their own insistence or with the help of a mental health provider or case manager.

> *The only reason we received discharge planning ...was at our insistence with the mental health clinic that [he] not be allowed home without*

discharge planning. It was only through the intervention of the mental health clinic that we were able to keep our son in the hospital long enough to get discharge planning...The hospital was ready to discharge him regardless of whether there was discharge planning or not. (Summit)

INTERAGENCY COLLABORATION

CHILDREN FALL BETWEEN THE CRACKS OF MULTIPLE AGENCIES

Lack of cooperation between Medicaid, schools, child welfare and other public agencies increases the difficulty of meeting children's needs. Parents in the focus groups viewed increasing communication and collaboration between all the public agencies involved with their child as a high priority.

Parents felt that each agency tried to avoid costs that another agency might cover. They said that because each agency expected the other ones to help their child and pay for those services, none of the agencies provided any assistance.

> *Nobody wants to supply the funding. They all want to pass the buck from one to the other. The school didn't want to make a referral because they would have had to fund it. Mental health doesn't want to make the referral because they would have been [the one] that had to fund [it]. DSS didn't want to make a referral, they would have had to fund it. So I have to go and yo-yo back and forth. I finally got them all in a meeting together and said, "Somebody better make the referral." (Summit)*

Several parents in Schoharie County said they were told that the only way to secure more intensive mental health services for their children with serious disorders was to relinquish custody to the state. While only a few parents in these focus groups had given up custody to the child welfare system, several families in each group had turned to juvenile justice for services. Desperate parents used the juvenile justice system to shorten the wait for the intensive services children needed.

> *I had to literally put my daughter in the PINS petition [to place a "person in need of supervision" under court jurisdiction] program because she was acting out and running away and nobody could help her. They would say she wasn't in crisis. So I went down to probation. I told him the situation and they said we can put her on a PINS petition. That's the only way she would have got better service. (Summit)*

Once the court system was engaged, parents reported immediate results.

> *We went through court with [the judge]; what [the judge] wants, [the judge] gets. (Syracuse)*

Using the juvenile justice system to access care created new problems for many parents. Families in New York City reported that some police officers were ill-prepared to deal with their child in a psychiatric crisis. Parents in Onondaga County reported that the juvenile justice system discontinues psychiatric medication for children and adolescents in custody.

> *So I had to really fight... almost close down the school fighting. But what happened between the time I began to advocate and be a terror was like literally nine months, ten months. And it took all the activity, it was like fighting with the school, fighting with the DSS. And I really got to the point and I said, look, I don't care, who pays for a psychological evaluation. Because the school was saying, "Well, DSS has to." DSS was saying, "It's the school's problem." And I just got mad. And I threatened them I was going to the board, I was going to the newspaper. It took a lot of really going through hell. And by the time it got to the board of education, they looked at me and they said, "How did you manage?" (Syracuse)*

PROVIDER ISSUES

SERVICES ARE NOT INDIVIDUALIZED

While some of the parents said that providers often help them learn what services might be available for their child, most families felt they were given little choice but to accept existing services. Principles of care for treatment of children with serious mental disorders from the federal Center for Mental Health Services emphasize that services should be designed to meet each child's individual needs.[7] However, according to the families in our focus groups, mental health providers in New York generally failed to tailor services to their children's characteristics, needs or interests. The parents said that even when they pointed out that these services were not helping their child, no changes were made.

It's like knocking your head against the wall. Nobody wants to seem to really listen. And it's like mind boggling that it takes as long as it does to get the right services for these kids. (Syracuse)

Faced with this situation, parents tried to make sure that their children were able to make the most of the services that were provided.

PROVIDERS BLAME PARENTS

Parents found systems slow to recognize their child's disorder. Several families, especially those in New York City, reported that mental health providers' initial response to their child's behavioral problems was to attribute the child's behavior to poor parenting skills or suspect some type of abuse. Even families with adopted children, who were likely to have behavioral problems related to their premature birth or maternal abuse of substances, said they were blamed.

My son suffers from phobias since he was a kid. He's going to be 15 and he still sleeps with the light. The doctors do look at me and ask me, "Has he been sexually abused?" Like pointing at me. I say, "Up to what I know, no." The counselor looking at me like he been sexually abused. Not that I know. I ask him, "Have you been sexually abused?" They pointed at me because of this phobia. That bothers me. (NYC)

Parents felt that providers were unresponsive to their needs for support and education as parents of children with serious emotional disturbances.

[The] doctor said my son has phobia because I had babied him too much. (NYC)

Parents expressed frustration about the responses to their situations in various child-serving settings, not just in mental health clinics. They said that professionals in other systems were also unresponsive to their child's need and were unaware of the fact that even very young children may have emotional disturbances.

Every day I had to go to school because they would call me to come and get this kid. And I'm saying, how long did you have this kid in this class, in this school and nothing was happening. Has anyone done an evaluation on her? It was like, no. (Syracuse)

PARENTS FELT DISRESPECTED

You're talked down to like you don't have any education, like you don't have, you can't possibly understand what's going on because you're on Medicaid. And I'm not, my son is. And so obviously you cannot be given information in the same – they talk to you in this kind of voice, whereas they talk to other people in this kind voice. They use small words instead of words that make sense. Just because you're on Medicaid. (Syracuse)

Many parents, particularly those in New York City and Onandaga County, said that some mental health providers and office staff treated them disrespectfully and felt that this was because their child was on Medicaid. Parents felt that some providers made assumptions about their families, thinking that families on Medicaid were uneducated.

They laugh at you. They mistreat you. They talk down their nose at you. It was a humiliating thing because it was the first time. And I just want some help. (NYC)

Some of the parents whose children were on Supplemental Security Income due to the seriousness of their child's mental disability wanted providers to understand that they were not welfare families. They resented the stigma they felt existed for a family seeking Medicaid services for their child.

NOTES

1 Bazelon Center for Mental Health Law (1999). *Making Sense of Medicaid for Children with Serious Emotional Disturbance.* Washington, DC: Bazelon Center for Mental Health Law.

2 Bazelon Center for Mental Health Law (2001). *Disintegrating Systems.* Washington, D.C: Bazelon Center for Mental Health Law.

3 New York State Department of Health. (2002, September 4). *New York State's Operational Protocol for the Partnership Plan [on-line].* Available: www.health.state.ny.us/nysdoh/mancare/partner/operatio/protw.htm.

4 CCF Coordinated Children's Services Initiative [Online]. http://www.capital.net/com/council/CCSI.html.

5 *2000 Census Data - Summary Profile for New York.* (2002, August 12) and *KIDS COUNT Census Data Online.* Available: www.aecf.org/kidscount/index/htm.

6. Giliberti, M. and Schulzinger, R. (2000). *Relinquishing Custody—The Tragic Result of Failure to Meet Children's Mental Health Needs.* Washington, D.C. Bazelon Center for Mental Health Law.

7. Stroul, B., and Friedman, R.A. (July 1986). *A System of Care for Severely Emotionally Disturbed Children and Youth.* Washington, D.C. CASSP Georgetown University Child Development Center.

POLICY RECOMMENDATIONS AND CONCLUSIONS

POLICY RECOMMENDATIONS

Gaining access to services—particularly intensive community rehabilitation services—appears extremely difficult for parents in New York. Several factors presented barriers, including:

- lack of appropriate providers;
- failure to identify and assess children early;
- an overemphasis on basic medical and clinical treatment.
- failure to individualize care; and
- poor collaboration across systems.

The home- and community-based waiver program, the Coordinated Children's Services Initiative and innovative programs such as the Friends program in New York City all offer children a broader package of services and are more supportive of families. The families in these programs reported greater access to services than the rest, but few of the state's children can benefit from any of these initiatives. As a result, most parents in the focus groups were left with limited care that achieves minimal, if any, result.

The focus groups suggest several ways to improve children's mental health services in New York, including:

• Substantially increase the number of home- and community-based waiver slots. Currently, only 610 slots are available for families across the entire state.

• State investment in intensive community rehabilitation services would help address the dearth of such services. Parents expressed a specific need for increased access to day treatment, in-home service providers, after-school programs, family support and summer programs.

• Develop a better response system to address children's mental health crises. Expanding the use of specialized mobile crisis teams could provide effective interventions that often can render expensive inpatient or residential care unnecessary.

• Consider developing additional systems of care similar to the Friends program and other initiatives, funded through the federal Center for Mental Health Services (CMHS). The state already has one CMHS grant in Westchester County, but other communities could benefit from such grants.

Because children with complex needs are unlikely to benefit from the short-term acute treatment normally offered through health maintenance organizations (HMOs), it is important to identify the children who ought to opt out of the limited mental health benefits available through managed care in favor of the services available under fee-for-service.

Some parents reported that they were able to opt out of this benefit and access child mental health services through fee-for-service, but many other parents were unaware of this option. Families need more information on this, and managed care entities should be obligated to refer children to the public mental health system where appropriate. In fact, parents of children with severe disorders who remained in their managed care entity reported the greatest dissatisfaction with New York Medicaid.

In other areas, a modest effort by the state could significantly improve services for children with serious emotional disturbances. For example:

• Greater emphasis on training of non-mental health professionals, such as teachers or child welfare caseworkers, could improve their understanding and recognition of emotional disturbances in children and enhance their ability to make appropriate referrals for care.

• Encouraging closer collaboration between mental health and primary care physicians to improve early identification of children who need mental health services would also be beneficial. Development of an effective screening tool for mental health and substance abuse issues for use in busy pediatricians' offices might

accomplish this and more effectively meet Medicaid's screening mandate.

• Developing and enforcing requirements for appropriate discharge planning from hospitals and residential programs can help families address transition issues when children with emotional disturbances return to life at home. Addressing plans for the child's transition back to his or her home school district and engaging community case managers prior to discharge can be extremely helpful to families.

• Adequately fund the Coordinated Children Services Initiative (CCSI), so as to encourage all counties to use it and strengthen it in the counties where it now operates, could greatly increase many children's access to needed services. Parents have found the coordination very helpful. CCSI is especially important for rural areas, which have so few child mental health resources.

In addition to suggesting areas where new policies might benefit children and families, the focus groups highlight some of the state's underlying difficulties in improving access to services.

Many parents in the focus groups discussed the dearth of psychiatrists, psychologists and other mental health providers who can furnish specialized mental health care. This is a greater problem in rural areas, but appears to present challenges in cities as well. The state could consider two strategies to deal with this issue: encourage providers to stay (or relocate) in the state or work around the lack of professionals by increasing the number of paraprofessionals to support the limited number of professionals and expanding access to mental health treatment in primary care settings.

Transportation issues also posed a significant barrier for many parents in the sizeable rural parts of the state. Development of services closer to where families live can be one answer to this problem, but when this cannot be done there may be more creative ways for the state to assist families in accessing various other forms of transportation. Or the state could provide short-term overnight accommodations when long distances must be traveled.

CONCLUSIONS

New York's Medicaid state plan includes a strong mental health benefit for children, covering most of the important community mental health services needed by children with serious emotional disturbances. However, the parents in our focus groups demonstrated that covered services are not accessible to all families who need them.

Services were too often denied or delayed until the child reached a point of crisis, at which point the parents found access to residential care and other intensive services similarly limited. Delayed identification and diagnosis and inappropriate responses to children and families have led to a crisis-oriented system for many of these families and, doubtless, many more in New York State. And when their children experienced a psychiatric crisis, the response was often inadequate.

Without adequate services, many of these children continue to deteriorate, despite the efforts of the loving and supportive families who participated in these focus groups. Too many of their children had already ended up in the juvenile justice system, where the outlook for their future is not good. Without change, more will probably follow that tragic route.

New York's children deserve better.

APPENDICES

APPENDIX A: FOCUS GROUP METHODOLOGY

Each of the focus groups ran for approximately two hours. Participants also completed a short survey about their children and their use of mental health services. As is standard focus group policy, participants were paid for their time. Since these are parents of children who need ongoing supervision, child care was also made available.

Participants were recruited through Families Together in New York State, a chapter of the Federation of Families for Children's Mental Health. Families Together is a nonprofit, parent-run organization that strives to establish a unified voice for children with emotional, behavioral and social disorders. Their mission is to ensure that every family has access to needed information, support, and services.

Parents were recruited through the distribution of flyers to programs serving children with serious mental disorders, such as family support groups, CCSI reference centers and county departments of mental health. Families were screened to ensure that their children were Medicaid-eligible and that they had a diagnosis of serious mental disaorder. No random selection was involved. All eligible families were invited to partipate.

The focus group followed the guidelines described by Richard Krueger in *Focus Groups: Second Edition: A Practical Guide for Applied Research*, 1994 by Sage Publications. The focus group topic guide was developed by the Bazelon Center with input from the staff at Families Together and the Bazelon Center's Institutional Review Board (IRB). The short survey, topic guide, consent form and research protocol were reviewed and approved by the Bazelon Center's IRB in January 2002. A stenographer transcribed each of the focus group discussions.

Although families of children who qualified for Medicaid were targeted for recruitment, a small number of families with children who were never enrolled or not currently enrolled in Medicaid during the past six months also attended the focus groups. Children not on Medicaid have been removed from the short background survey totals and their parent's quotes are not included in the report.

Participants in two of the focus groups (Schoharie and Onandaga Counties) were asked about their awareness of children's mental health services under Medicaid. Due to the large size of the New York City group, we did not have time to ask the group this question.

For the most part families were aware of the mental health services available to children and adolescents. More than 70 percent knew of the availability under Medicaid of six services: crisis services (100 percent), therapy for a child (100 percent), medication (90 percent), case management (86 percent), mental health services at the child's school (81 percent) and mental health programs separate from school (71 percent). About half the families were aware that therapy for the family was available. Most families, however, were unaware of several crucial services for children: family support (62 percent did not know of the service), day treatment (64 percent), therapeutic foster care (64 percent), independent living skills (81 percent) and teaching family homes (100 percent).

APPENDIX B: ADDITIONAL DATA TABLES

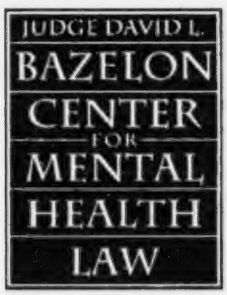
TABLE 1: Mental Health Services Received in 2002

Service	Percent
Services received by 76% - 100% of families	
Therapy for child	79%
Services received by 51% to 75% of families	
Medication management	61%
Case management services	61%
Family support	59%
Crisis services	58%
Mental health services at child's school (during or after school)	54%
Services received by 26% to 50% of families	
Mental health programs separate from school (such as day treatment)	29%
Services received by 0% - 25% of families	
Independent living skills	23%
Therapeutic foster care	9%
Teaching family homes	3%

TABLE 2: Family Awareness of Mental Health Services

Service	Percent
Services known by 76% - 100% of families	
Crisis services	100%
Therapy for child	100%
Medication	90%
Case management services	86%
Mental health services at child's school (during or after school)	81%
Services known by 51%-75%	
Mental health programs separate from school (such as day treatment)	71%
Therapy for family	52%
Services known by 26% - 50% of families	
Family support	38%
Day treatment	36%*
Therapeutic foster care	36%*
Services known by 0% - 25% of families	
Independent living skills	19%
Teaching family homes	0%

* Indicates percentage in only one focus group



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